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ABSTRACT

The last of a six-volume series on community adjustment of deinstitutionalized mentally retarded people provides a summary of the study's findings and policy recommendations. Findings are described for each of the five preceeding volumes (sample findings in parentheses): a review of the literature (mentally retarded persons have made reasonably good adjustments but problems remain); a profile of national deinstitutionalization patterns 1972-1974 (a larger percentage of the children and youth released were severely or profoundly retarded than the percentage of adults released); deinstitutionalization procedures of 10 institutions (nine institutions reported pre-release programs designed to prepare residents for community placement); community experiences of the discharged residents (group homes were the most common residential setting of non-returnees while foster homes were the most common setting for returnees); and factors associated with community adjustment (level of retardation and age will have direct impact on the person's community adjustment). Recommendations are made for nine policy areas, including institutional release policies for severely and profoundly retarded residents, preparation of residents for community living, and availability of community resources and programs. (CL)

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Contract No. OEC-0-74-9183

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FINDINGS AND RECOMMENDATIONS

December, 1976

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Volume VI of:

A Study of the Community Adjustment
of Deinstitutionalized Mentally Retarded Persons

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In July, 1974, Abt Associates was awarded a contract by the Bureau of Education for the Handicapped of the United States Office of Education to conduct an assessment of the adjustment of deinstitutionalized mentally retarded people to community life (Contract No. OEC-0-74-9183). The present volume is one of a six-volume series produced over the course of the project to describe deinstitutionalization procedures of institutions and community adjustment experiences of mentally retarded persons. We are deeply indebted to many people for their cooperation and assistance in all phases of this project.

First, we wish to give special thanks to our Project Officer in the United States Office of Education's Bureau of Education for the Handicapped, William Johnston, for providing support and guidance to us throughout the course of the contract, and to Max Mueller, Chief, Research Division, BEH.

The Abt Associates research staff who assisted in this project worked long and difficult hours to prepare, analyze, and report the data in these volumes. First, we wish to thank Patricia Cook, who served as the Project Director of this study from July, 1974 to May, 1975. Special thanks go to Diane Stoner, Supervisor of Field Operations, and to Jaime Grubin and coders from the Survey Design Group for pre-coding our instruments and subsequently coding the data; to Joe Clark, Sandy Friedman, and Paul Robertson for their invaluable help in preparing the complex data base and carrying out the computer work; to Jim Hoell and Karen Schneiderman for helping organize the data into meaningful tables and charts; and to Kathy Moss and Paul Robertson for assistance in writing up our findings.

We are expecially grateful to Professor Norman R. Kurtz of the Florence Heller School for Advanced Studies in Social Welfare, who served as an on-going consultant on this project. He was helpful in various phases of the project, particularly in reviewing our instruments, developing and carrying out our analysis plan, and reviewing our working documents.

Corporate staff at Abt Associates who deserve thanks for their support and guidance are Andy Anderson, our contract management reviewer, and Peter Miller, Education Area Manager and Vice President.

The study involved two major field efforts: 1) visits and interviews by field staff at 10 selected institutions serving mentally retarded persons; and 2) visits and interviews by field staff with the 440 deinstitutionalized clients and their families. The field staff worked enthusiastically and effectively in collecting the data, sometimes under difficult field conditions and time constraints. We wish to thank the field staff who conducted the site visits to the ten institutions--Marjorie Scarlett, Laurie Stewart, and Bonnie Wilpon--as well as the staff who conducted interviews with deinstitutionalized clients and their families--Sharon Alperin, Joel Braun, Amy Cicala, Michael Clifford, Barbara Epstein, Eleanor Franklin, Lois Gerardi, Ellen Hartford, Lauri Lewis, Vicki Peters, John Schlichte, Suzanne Simenson, and Jan Valley.

Special thanks go to the Mohawks and Squaws, a consultant group of mentally retarded persons, and to Adrienne Glenn in particular, who helped sensitize and train our field staff to the process of interviewing mentally retarded persons. We are also grateful to the institutions and persons who assisted us in pre-testing instruments and questionnaires--particularly the staff at Monson State School, Monson, Massachusetts, and the staff at Seaside Regional Center, Waterford, Connecticut, and the host of families, group home staff, and deinstitutionalized clients.

We wish to thank the 154 institutions which responded to our initial mail survey and particularly the staff at the 10 institutions participating in this study. Participation required a great deal of time and effort on their part, with little promise of returns which could directly benefit them. Their motivation for participating was based on a desire to assist in a research project which they felt was greatly needed. We hope that our study reports meet their expectations and will be helpful in pareparing training programs and placing clients in community settings. The institutions participating were:

Arlington Development Center
Arlington, Tennessee

Beatrice State Home
Beatrice, Nebraska

Belchertown State School
Belchertown, Massachusetts

Brainerd State Hospital
Brainerd, Minnesota

Brandon Training School
Brandon, Vermont

Northern Wisconsin Colony and Training School
Chippewa Falls, Wisconsin

Polk State School and Hospital
Polk, Pennsylvania

Suffolk Developmental Center
Suffolk, New York

Sunland at Tallahassee
Tallahassee, Florida

Utah State Training School
American Fork, Utah

Above all, our praise and thanks go to the 440 deinstitutionalized clients and their families who participated in this study. They spent long hours with our interviewers providing difficult information on community adjustment experiences. As with the participating institutions, there were no direct benefits to them for participating in the study. Without their efforts and insights, a report such as this could not have been written. We can only hope that the findings and recommendations of this study might facilitate the community adjustment of persons who are released from institutions in the future.

Elinor Gollay, Project Director
Ruth Friedman, Deputy Project Director
Marty Wyngaarden, Research Analyst

PREFACE: PROJECT OVERVIEW

Objectives

This report is based on a study conducted by Abt Associates Inc. for the Bureau of Education for the Handicapped of the United States Office of Education (Contract No. OEC-0-74-9183). The overall purpose is to assess the adjustment of deinstitutionalized mentally retarded people to community life. The objectives are six-fold:

1. to review the criterion measures and predictors of community adjustment used in studies of mentally retarded persons and to analyze the research issues related to these projects. The findings of this review are contained in Volume I: Approaches to Defining and Measuring the Community Adjustment of Mentally Retarded Persons--A Review of the Literature.

2. to describe the current patterns of deinstitutionalization based on a mail survey of 250 institutions across the nation involved in deinstitutionalizing mentally retarded persons. Volume II: Profile of National Deinstitutionalization Patterns 1972-1974 summarizes the findings of this survey.

3. to describe the deinstitutionalization procedures and policies of 10 selected residential institutions serving mentally retarded persons based on field visits made to these facilities by project staff. The findings of these visits are published in Volume III: Case Studies of the Deinstitutionalization Procedures of Ten Selected Institutions Serving Mentally Retarded People.

4. to describe the community experiences of mentally retarded persons, based on interviews with 440 clients (released from the selected institutions described in objective 3) and their "families" (e.g., parents, foster parents, guardians, or whoever was providing care and supervision for the client in the community setting). This descriptive data is presented in Volume IV: Descriptive Data on the Community Experiences of Mentally Retarded Persons.

5. to determine what institutional, client, and community factors contribute to successful community adjustment based on the interviews described in objective 4 and on institutional data collected during the field visits to the ten institutions. Volume V: An Analysis of Factors Contributing to Community Adjustment presents the findings of this analysis.

6. to summarize the findings of the previous 5 volumes and to provide recommendations to USOE for further research related to deinstitutionalization based on the analysis of the data collected according to the objectives described above. These findings are published in Volume VI: Executive Summary--Overall Findings and Recommendations.

Overall Research Design

The overall research design employed in this study is depicted graphically in Table A. As can be seen from the table, there were four major phases to the study design: 1) conceptualization; 2) instrument design; 3) data collection; and 4) analysis and report writing. The findings reported in Volumes 1-6 were based upon the procedures undertaken in each of the four phases. In order to present an overall picture of the research design, the phases will be briefly described in this section. More detailed information on these phases as they relate to each of the specific volumes is presented in the "Methodology" section of each of the first five volumes.

Conceptualization

The first major phase involved developing a conceptual model of deinstitutionalization and the community adjustment process. First, a review of the literature was conducted. Based on the findings of this review (reported in Volume I), a model was developed setting forth the study's assumptions about the process of deinstitutionalization and community adjustment. The model included nine sets of variables which encompassed the major characteristics of deinstitutionalization and the community adjustment experiences. The nine sets of variables are listed at the bottom of Table A (see "a" in Table A). More specific information on the content of these variables and their role as independent and dependent measures is contained in the "Methodology" section of each of the first five volumes.

Instrument Design

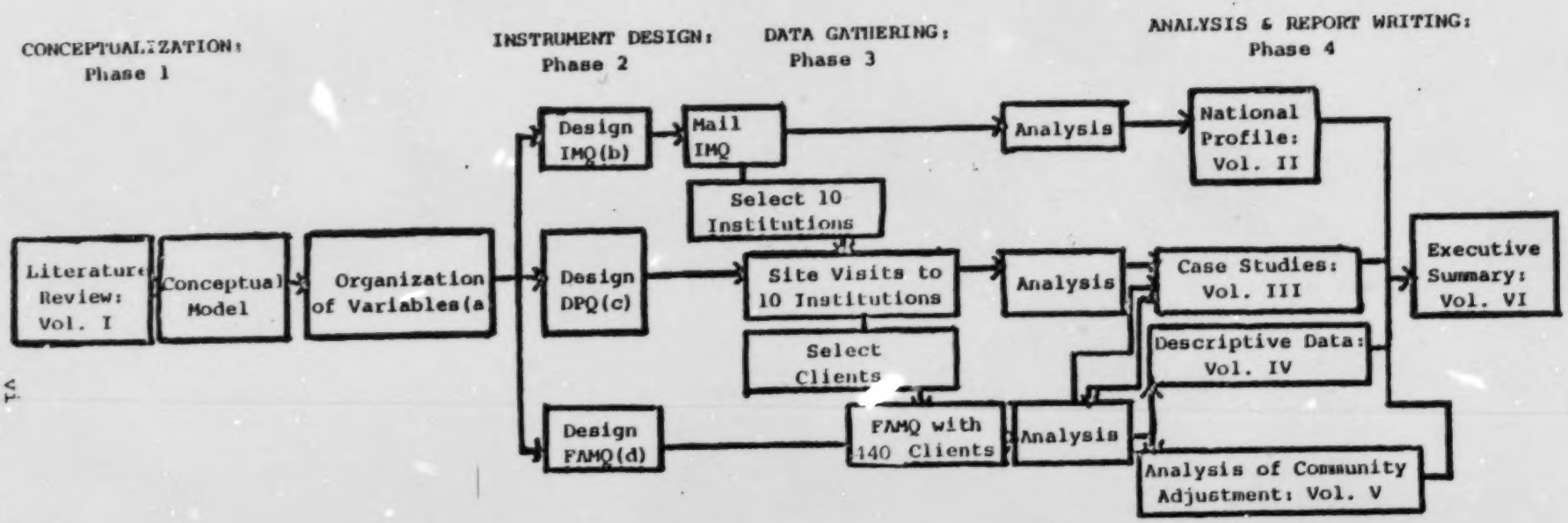
Three groups of instruments were designed to collect data on the nine variable sets:

1. Institutional Mail Questionnaire (IMQ) -- a mail questionnaire designed to obtain information on the deinstitutionalization procedures and release patterns of 250 institutions across the nation serving mentally retarded clients.

2. Deinstitutionalization Procedures Questionnaire (DPQ) -- a questionnaire designed to survey ten institutions selected for in-depth case study descriptions regarding deinstitutionalization and pre-release policies, procedures and programs.

TABLE A.

OVERALL RESEARCH DESIGN.



(a) Sets of Variables

- Client Characteristics
- Institutional Characteristics
- Community Characteristics
- Residential Characteristics
- Day Activity Experiences
- Residential Experiences
- Services and Training
- Social & Civic Activities
- Problems & Interpersonal Relationships

(b) IMQ Data Areas

- Residential Population
- Release Patterns
- Pre-Release/Post-Release Services
- Institutional Clearance Procedures for Study

(c) DPQ Data Areas

- State Policies/ Legislation
- Client Assessment Procedures
- Pre-Release Programs
- Release Procedures
- Follow-Up Procedures and Support

(d) FAMQ Data Areas

- Interview with Client
- Interview with Family
- Adaptive Behavior Scale
- Client Data Recording Form
- Final Comments Sheet

3. "Family" Questionnaires (FAMQ) -- a series of instruments designed to obtain data on the community adjustment experiences of deinstitutionalized clients living in the community. The types of instruments included in the Family Questionnaire are listed at the bottom of Table A (see "d" in Table A). The instruments included an interview questionnaire to be administered to the deinstitutionalized client; a questionnaire administered to the client's family; an Adaptive Behavior Checklist (ABS) measuring the functional level of the client; a Client Data Recording Form (CDRF) obtaining demographic data from institutional records about the client (e.g., age, number of years institutionalized, date of discharge, etc.); and a Final Comments Sheet (FCS) to record the interviewer's impressions.

Data Gathering

The three sets of instruments described above were administered to the appropriate respondents in a sequential fashion. First, the IMQ was mailed to 250 institutions serving mentally retarded persons across the nation. Ten institutions were selected for in-depth case study descriptions (see Methodology" sections of volumes for description of selection procedures used for IMQ respondents). The 10 institutions were then visited by project staff to collect data using the DPQ. Based on the data and on further contact with institutional staff, 440 deinstitutionalized clients released from their institutions were selected for study. (See "Methodology" section of volumes for descriptions of these selection procedures.) Finally, the FAMQ series of instruments was used to gather data on study group clients.

Analysis and Report Writing

The data described above were analyzed and reported in several ways. The findings based on IMQ data are reported in Volume II: Profile of National Deinstitutionalization Patterns, 1972-1974. The data obtained from the DPQ were analyzed in two ways: 1) case study descriptions of the individual institutions and a cross-case study summary which is reported in Volume III: Case Studies of the Deinstitutionalization Procedures of Ten Selected Institutions Serving Mentally Retarded People; and 2) portions of the DPQ data served as independent variables for the analysis reported in Volume V; An Analysis of Factors Contributing to Community Adjustment. Similarly, the FAMQ data were analyzed in several ways: 1) data on the community experience of clients in the study group are reported descriptively in Volume IV: Descriptive Data on the Community Experiences of Mentally

Retarded Persons and also in the final chapter of each institution's case study description in Volume III; 2) FAMQ data are organized into independent and dependent measures of community adjustment and reported in Volume V: An Analysis of Factors Contributing to Community Adjustment. All of the data collected and reported in Volumes 1-5 were then analyzed in terms of their implications for overall study findings and recommendations. These overall findings and recommendations are reported in this report, Volume VI: Executive Summary.

Organization of the Volume

This volume presents summaries of each of the previous volumes. It is intended to give the reader an overview of the major findings. Section 1.0 presents a summary of the literature review (Volume I). Section 2.0 reports the major trends in deinstitutionalization between 1972-1974 based on Volume II of this study. Section 3.0 presents a cross-case study summary, which describes the salient features of the 10 institutions whose in-depth profiles are found in Volume III of this study. Section 4.0 reports the major descriptive findings of the institutional and community experiences of the 440 clients interviewed in this study. More detailed descriptive data can be found in Volume IV. Section 5.0 reports the major findings of the analysis of factors contributing to community adjustment (Volume V). Finally, Section 6.0 presents the policy recommendations and conclusions based on the findings and outlines future research efforts needed. A glossary of terms used throughout this report is appended to this volume.

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APPENDIX

1.0 SUMMARY OF VOLUME I: APPROACHES TO DEFINING AND MEASURING THE COMMUNITY ADJUSTMENT OF MENTALLY RETARDED PERSONS: A REVIEW OF THE LITERATURE

1.1 Purpose of the Report

The purpose of this report was to examine studies which have attempted to measure the community adjustment of mentally retarded persons, focusing on the definitional and measurement issues related to these projects. There were two major reasons for conducting this literature review. The first was to integrate the findings of previous studies in order to develop a responsive study design for use in the Abt study and the second reason was to present such an integration of various studies that would be of use to persons developing programs and services to mentally retarded persons.

1.2 Integration of Findings of Studies

It is difficult to summarize the findings from various community adjustment studies because the studies are so diverse in purpose, methodology, samples, etc. However, certain general conclusions can be made. The most important conclusion is that a large group of mentally retarded persons appears to be adjusting quite successfully to community living according to a wide variety of criteria. Frequently, the public's reaction to this overall finding has been as interesting as the finding itself. Many people have been shocked or at least surprised at the large number of mentally retarded persons faring well in the community. The element of surprise can be attributed to the fact that traditionally, there have been low and negative expectations regarding the adjustment potential of mentally retarded persons. Therefore, when mentally retarded persons succeed, people are surprised.

This phenomenon is best reflected in the first significant study of the community adjustment of mentally retarded persons, an institutional follow-up conducted by Walter Fernald (1919) on those inmates who escaped or were reluctantly discharged during the 1890-1914 period from Waverly State School in Massachusetts. During this time period, the height of the eugenic alarmist movement, almost no persons were placed in the community with the sanction of the institution. The general attitude toward mentally retarded persons at the time of this study can be summarized in the following quotation

from a paper presented by Fernald (1904) at the National Conference of Charities and Correction:

> No method of training or discipline can fit them to become safe or desirable members of society. They cannot be "placed out" without great moral risk to innocent people. These cases should be recognized at an early age before they have acquired facility in actual crime and permanently taken out of the community.... (p. 7)

He specifically described the dangers posed by mentally retarded women:

> Feeble-minded women are almost invariably immoral and if at large, usually become carriers of venereal disease or give birth to children who are as defective as themselves...." (p. 8)

The Fernald follow-up study was the first in a long series of studies, most of which established that mentally retarded persons were in general faring better in the community than had been previously expected. According to Davies (1959), it was "little short of a revelation" in the Fernald study that "there was found among the women subjects, no preponderant amount of delinquency, so few illegitimate children, and so few children in general, that many were good wives, and that many more were materially contributing to their maintenance." (p. 110) In fact, Fernald hesitated for two years to publish the findings of this study because of its shocking results. The implication of the findings was highly controversial -- if mentally retarded persons were faring well in the community without the sanction or support of the institution, what levels of adjustment might they achieve with training and staff support?

The findings of other studies, similar in nature ot Fernald's conclusions, became less shocking as society's attitudes toward the mentally retarded changed and the perception of the potential of mentally retarded persons to grow and develop changed. It is interesting to trace historically the types of follow-up studies which have been conducted and the nature of their findings.

McCarver and Craig (1974) in their review attempted to integrate the findings of 44 studies conducted from 1918-1970, based on one criterion of adjustment: remaining in the community (success) as opposed to returning to the institution (failure). Recognizing the limitations of such a cursory

analysis, McCarver and Craig used it solely as a way to summarize the overall success rate of a diverse group of studies.

The median success rate (measured by the criterion of remaining in the community) found for the 44 studies was 74%. The mean success rate, based on all 9116 subjects in these 44 studies, was about 69%. McCarver and Craig then divided the studies into 4 time periods in which they were conducted and plotted the success rate of the studies in these time intervals: 72% success rate from 1918-1935, 89% from 1936-53, 65% from 1954-59, and 53% from 1960-70. McCarver and Craig offer many interesting interpretations of these data which will not be possible to report in detail in this paper. However, one interpretation will be noted here -- that of the declining success rates since 1953. The increasing complexity of society and the decreasing ability levels of those remaining in institutions were offered by McCarver and Craig as reasons for the decreasing success rates in this time period.

A finding related to the general conclusion in most studies that a large majority of mentally retarded persons are adjusting well has been that the stability of their adjustment tends to increase over time. The longitudinal follow-up studies offer a unique opportunity to trace the adjustment patterns of individuals over time. All of the selected longitudinal studies confirm this trend of increased stability over time. For example, this conclusion was drawn in the Baller, Charles & Miller study (1967), in which three groups of subjects (one "low" mentally retarded group, one "middle" mentally dull or borderline group, and one "high" normal group for comparison) were followed up in their mid-lives after having originally been studied in their early lives in the 1930s. The authors noted that "over time, the range of capability for all groups tended to increase" and "...with maturity, the subjects were able to profit from improved economic conditions, and have become more self-sufficient." (p. 446) Similarly, Fairbank (1933) noted that her subjects demonstrated a "remarkable degree of stability," followed up after an interval of 17 years. Several predictive studies found the variable length of time placed in the community to be significantly and positively related to community adjustment.

The comparative follow-up studies provide a unique perspective on the adjustment process, because in many of these studies, the adjustment experiences of mentally retarded subjects have been compared to groups of non-retarded persons. Only in these studies can be determined how the adjustment experiences of mentally retarded persons compare to the so-called "normal" population's experience.

In Kennedy's study (1962), information on the personal, social and economic adjustment of a group of mentally retarded subjects and a group of normal controls were collected. She noted that the overwhelming majority of both subjects and controls had made acceptable and remarkably similar adjustments in all areas. There were, however, some differences between the subject and control groups (with the subjects' adjustment scores lower than the controls' on some variables), but these differences were considered to be of degree, rather than of kind. For example, Kennedy found that the subjects were slightly less active in their degree of participation in social activities than the controls, but the kinds of organization to which subjects belonged did not differ markedly from those in which controls were members.

Similarly, Baller, Charles and Miller (1967) found that the members of their low group fared much better than they had expected, but in comparison with the other two groups originally identified as dull and normal, they continued to be in an inferior position in most respects, with the ratings of the three groups taking generally a stair-step form.

It is important to stress, however, that all is not "rosy" in the pictures that have been portrayed of the adjustment experiences of mentally retarded persons. A majority of subjects seemed to be adjusting well in the selected studies. But a significant number have <u>not</u> adjusted successfully. And of those who have adjusted well according to the wide variety of criteria used in different studies, various levels of adjustment can be noted <u>within</u> the sample groups, some experiencing less success than others.

It is often in the area of social adjustment where mentally retarded persons have experienced the greatest problems. For example, in Saenger's followup study (1957) of 520 mentally retarded adults who were former pupils in New York City classes for the "trainable retarded," he found that only ½ of the group were said to have friends, ¼ had friends of the opposite sex,

and 1/3 were able to leave their immediate neighborhood or take buses and subways by themselves.

Similarly, Lambert (1974b) summarized the findings of his follow-up of 373 persons living in Ontario:

> About one-half of these adults had never worked....Most of them do very little around the house, and scarcely participate in activities in the home or outside of it....Some of the barriers which they identified to a more full participation in life were the absence of other persons to help them around in the community and the scarcity of other people with whom they might interact...." (p. 15)

Edgerton also points to the social isolation which many mentally retarded persons experience in living in the community -- particularly to the stigma of having been defined as mentally inferior and the intense need to pass as "normal." Obviously, the community adjustment of mentally retarded persons has not been a complete success story. As E.A. Doll, developer of the Vineland Social Maturity Scale and one of the forefathers in the field of mental retardation summarized in 1932:

> What becomes of the non-institutionalized feeble-minded? Many of them continue to receive financial support and social supervision of their families so successfully that they do not become social problems outside of their homes. On the other hand, neither do they become social successes. They live in a sort of purgatory between success and failure, rising and falling with the tide of circumstances....apparently, they find some humble niche in society which they can fill without becoming such a social menace that society becomes gravely concerned about them. (As quoted in Kennedy, 1962, p. 70)

Similarly, Edgerton (1967) concluded in his study: "These former patients have not become pillars of society, but neither have they been conscious in their opposition to social norms or to law." (p. 142)

The findings of the studies reviewed in this report point to this "purgatory between success and failure." Many mentally retarded persons manage to exist and "make it" in the community but the quality of their lives had been deficient in many aspects. In conclusion, it can be said that overall, mentally retarded persons have made reasonably good adjustments to many environments in which they function. However, adjustment problems continue to exist. More research should be undertaken which will attempt to

distinguish between the adjustment experiences of the successful and unsuccessful groups. Only by analyzing the unsuccessful experiences can we gain insight into the total adjustment process and the supports necessary to assist mentally retarded persons in adjusting well to community living.

1.3 Future Outlook on Community Adjustment of Mentally Retarded Persons

What is the future outlook for mentally retarded persons living in the community? According to many experts the future is not encouraging. Economic and social trends point to an increasingly complex and mechanical society which poses special problems for the mentally retarded.

For example, according to Goldstein (1964), the occupational picture for the retarded is far from encouraging:

> Occupational categories once the province of the retarded have been decreasing markedly in the past half-century.... much of the disappearance of jobs for the retarded may be attributed to technological changes wrought by automation and mechanization in industry, on the farm, and in homes. Competition for remaining jobs has become more keen because of the large labor pool available for such work. (p. 254)

Society is becoming increasingly complex socially, as well. For example, Skaarbrevik (1971) points to the urbanization of society which he feels has made "...social life more intricate, hampering social interaction of retarded individuals with other people...." (p. 563) Similarly, Krishef (1959) found the urban social environment to be a major delimiting factor in the community adjustment of mentally retarded persons. In his study, subjects living in rural areas adjusted more successfully than subjects living in urban environments. He interpreted this finding in the following manner:

> In the urban community, the retarded person meets people more frequently, has more demands made upon him in social interaction, and is perhaps more likely to encounter criticism and ridicule. The emotional and social pressures upon the ward and the resultant frustration may ultimately lead to more frequency of unsuccessful adjustment among the mentally retarded. (p. 864)

It becomes apparent that the increasing complexity of society has had an effect on the occupational opportunities and social life of mentally retarded persons. In future studies, more attention should be paid to the relationship of these conditions to the community adjustment of mentally

retarded persons. Skaarbrevik stressed the need for a more dynamic view both of the problems of adjustment for the mentally retarded persons and the research in this field -- a view which stresses the interaction between the individual and his community:

> Sociological, political and economic variables, in addition to psychological variables, could give an interesting and useful picture of the problems of the retarded from a social point of view. These variables could describe the communities where the retarded are living along a simplicity-complexity dimension, and also could provide new suggestions about how these problems can be solved in the most efficient way...." (p. 563)

2.0 SUMMARY OF VOLUME II: PROFILE OF NATIONAL DEINSTITUTIONALIZATION PATTERNS 1972-1974

2.1 The Purpose of the Report

This volume describes national patterns of the community placement of deinstitutionalized mentally retarded persons between 1972 and 1974. The information reported was obtained in the fall of 1974 through a mail questionnaire (Institutional Mail Questionnaire) sent to approximately 250 institutions serving mentally retarded persons across the country. One hundred and fifty-four institutions responded, and it is their responses which are summarized in this section. The report described 13,158 persons released in terms of their individual characteristics (age and level of retardation); the type of community placement to which they were released (natural home, foster home, group home, or independent living); and the characteristics of the releasing institutions (population, auspices, geography, pre-release and post-release services). Only those who were released to community settings, who were between the ages of 6 and 40, and had lived in the institution for at least two years prior to their release were included in the analysis. An additional 6,015 persons met the age and residential criteria, but were not included because they were released to other institutional settings rather than to community settings. In addition, there were other releases that did not meet the age and residential criteria, i.e., persons over 40 or under 6 years of age, as well as persons who had not resided at the institution for at least two years.

2.2 Summary of Sample Characteristics

The Institutional Mail Questionnaire collected information from 154 institutions serving mentally retarded people, nearly three-quarters of which were public facilities. These institutions were located throughout the continental United States with the North Central region having the greatest number of responding institutions (30% of the total sample). The largest institutions were located in the Northeast and South. Three-quarters of the institutions serving less than 150 residents were privately controlled and located in the North Central region. Nearly three-quarters of the population residing in the institutions were mentally retarded persons between the ages of 6 and 40 years.

Pre-release programs were available in more than 90% of the responding institutions during each year under study. The most common pre-release program across all three years was educational training, while the least common was pre-release independent living units. The average number of pre-release programs was about four for each year per institution. The number of pre-release programs increased notably between 1972 and 1974.

Post-release services were available in roughly three-quarters of the institutions during the period under study. The most frequent service provided was respite care in 1972 and social work in both 1973 and 1974. Over half the institutions reported an average of three to four post-release programs per year. The number of post-release services did not vary appreciably between 1972 and 1974.

For both pre- and post-release services, institutions with fewer than 500 residents had fewer services. The largest number of services tended to be in the medium large institutions of between 500 to 999 residents. The largest institutions (over 1,000 clients) had fewer services than these medium large institutions, but more than the smaller ones.

2.3 Summary of Target Client Release Patterns

2.3.1 Overall Target Client Releases

Approximately one-third of the target clients released from these institutions were children and youth (ages 6 to 18 years); adults (ages 19 to 40 years) comprised the remainder of the sample of target clients. Three-quarters of the released target clients were mildly retarded or moderately retarded persons. Twenty percent were severely retarded and the remaining 5% were profoundly retarded.

The most common type of community placement was to natural/adoptive homes (40%); over a quarter (29%) of the released clients were placed in group homes. The largest single group of target clients who were released during the 1972-1974 period were mildly retarded persons placed in natural/adoptive homes (17% of the total target group). The second most frequent

2.3.2 Comparison of Children and Youth and Adult Releases

It is interesting to note that a larger percentage of the children and youth released were either severely or profoundly retarded (30%) than of the adults released (23%). This perhaps reflects the greater optimism towards preparing severely retarded children for independence than exists towards adults, and perhaps is also a reflection of the growth of day (school) programs for children regardless of level of retardation. Finally, it may also represent a greater willingness for community persons to accept responsibility for severely retarded children and greater reluctance to do so for severely handicapped adults.

It is also interesting to compare the types of placements for both age groups. While over half (59%) of the children and youth releases were to natural/adoptive homes, only about a third (32%) of the adult group were so placed. Another third of the adult group were placed in group homes as compared to 15% of the clients under age 19. Not surprisingly, independent living situations received many more adults than children and youth.

2.3.3 Relationship Between Community Placement and Level of Retardation

Several interesting patterns developed in the types of residential settings to which the target clients were released. Natural/adoptive homes received more than half of all children and youth releases, regardless of the level of retardation. However, placement in natural/adoptive homes for adults increased as the level of retardation increased. For example, less that 30% of the mildly retarded adults were released to their natural/adoptive homes, whereas close to 50% of the profoundly retarded adults released were placed in natural/adoptive homes.

Foster homes received larger proportions of moderately and severely retarded clients regardless of age than they did of the mildly and profoundly retarded released populations. Group homes tended to receive an incrementally larger proportion of children and youth residents within each level of retardation as the severity of the level increased. For example, 11% of the mildly retarded children and youth were placed in group homes; 23% of the profoundly retarded children and youth were so placed. For adults, on the other hand,

more than one-third of all releases within each category of retardation were placed in group homes.

Independent living situations received smaller proportions of residents as the severity of the level of retardation increased. For example, of the mildly retarded adults released during the period under study, 20% were placed in independent living situations, while less than 1% of the profoundly retarded adults released from the sample institutions were so placed. Virtually no children or youth who were moderately, severely, or profoundly retarded were placed in independent living situations.

When level of retardation was considered, it was found that nearly three-quarters of all mentally retarded people released to natural/adoptive families, for both children and youth and adults, were either mildly or moderately retarded. Within each residential setting, mildly or moderately retarded clients comprised well over half the total number of clients released to each setting.

The vast majority of clients of all ages released to independent living situations were mildly and moderately retarded. Virtually no severely or profoundly retarded adults or children and youth were released to independent living situations. Releases to group homes were fairly evenly distributed within each level of retardation for children and youth. For adults, however, group homes received few profoundly retarded clients.

2.4 Summary of Institutional Characteristics and Target Client Releases

Not surprisingly, institutional size was associated with the number of target client releases from the responding institutions. While almost half of the facilities served 500 or more clients, nearly three-quarters of the released target group were from these facilities. More interesting was the relationship between institution size and the release patterns. A larger proportion of clients released from large institutions were adults and were severely or profoundly retarded than clients released from small institutions. Smaller institutions more frequently placed children and youth in natural/adoptive or foster homes while larger institutions had a greater proportion of releases to group homes. Adult placements were not strongly affected by the size of the releasing institutions.

Public institutions (72% of the sample) were, in general, much larger than private institutions, and released 94% of the target clients during the period under study. Thus, institutional size confounds the number of released clients from public and private facilities though not necessarily the types of clients or the types of settings to which they were released. It was found that private facilities released greater proportions of children and youth and greater proportions of mildly retarded clients than did public facilities. Public facilities released clients to more varied settings than private facilities, a tendency especially notable for adult releases.

When geographic location was considered, it was found that Southern institutions released primarily mildly retarded clients to natural/adoptive homes and that about 40% of Southern releases were children and youth. The Northeast released mostly mildly retarded clients but utilized more varied community settings than other geographic regions. The North Central region released over half its adults to group homes, nearly three-quarters of whom were either mildly or moderately retarded. However, nearly 40% of the children and youth released from the North Central institutions were severely or profoundly retarded with natural/adoptive homes receiving the majority of this age group. Western institutions showed the most even distribution of releases by level of retardation and types of community placements of any of the geographic regions.

Institutional size and the number of pre- and post-release services were related, with larger institutions offering a higher average number of services and programs than smaller institutions. Releases from institutions with different average numbers of services were not notably related to the number of services or programs, except when those institutions offering no services were compared with those institutions offering any number of services. Post-release services were not related to the proportion of releases, regardless of age, who were placed in natural/adoptive homes, in that as the number of post-release services increased, the proportions of released clients to this type of setting tended to decrease.

3.0 SUMMARY OF VOLUME III: CASE STUDIES OF THE DEINSTITUTIONALIZATION PROCEDURES OF TEN SELECTED INSTITUTIONS SERVING MENTALLY RETARDED PEOPLE

3.1 Purpose of the Report

The purpose of this summary is to describe the major characteristics, programs, and policies of the ten institutions, based on the data presented in the individual case studies. This is not intended to serve as a statistical analysis of the data; rather, the summary will describe narratively the deinstitutionalization trends present at these ten institutions, highlighting major differences and similarities wherever possible. The summary will be presented according to the organizational format of the individual case studies with the following sections:

- 3.2 Overview
- 3.3 State Context
- 3.4 Client Assessment Procedures
- 3.5 Pre-Release Programs
- 3.6 Release Procedures
- 3.7 Follow-up and Support Services
- 3.8 Released Client Profile
- 3.9 Profile of Re-Admitted Clients
- 3.10 Summary

3.2 Overview

All ten institutions were public facilities serving mentally retarded children and adults. With the exception of one institution, the facilities served only persons whose primary handicapping condition was mental retardation; the exception to this policy served, in addition, mentally ill and chemically dependent persons. Three institutions were responsible for serving residents from throughout the state; the other institutions were one of several within their state and therefore served a particular geographic region within their state.

The mean residential population of these facilities in the Spring of 1975 was 965, with a range from 360 to 2,300 residents. Most of the institutions (eight of the ten) experienced declining residential populations

during the 1972 - 1975 period. The percent decrease among the institutions ranged from 7% to 30%. Two institutions experienced population increases over the 1972 - 1975 period--one increased by 7% and the other by 9%.

Not only did the size of the residential population change during the period under study, but the level of retardation of residents changed dramatically as well. The overwhelming majority of the institutions reported shifts in their population from mildly and moderately retarded residents to severely and profoundly retarded individuals. At eight of the ten institutions, the percent of mildly and moderately retarded residents decreased and the percent of severely and profoundly retarded persons increased during the 1972-75 period. Most institutions felt that this shift was occuring because the most capable and least severely handicapped residents were released to community settings, while the more severely and profoundly retarded residents remained since community placement opportunities for them are generally less available. It may also be that once less severely retarded persons are released, the vacancies are being filled with more severely retarded clients.

Other characteristics of the population--sex, age, other additional handicaps of the residents--did not change significantly during the period under study. The distribution of males and females remained approximately equal across the facilities. The percentage of children (aged 18 or under) to adults (aged 19 or older) served at the ten institutions varied. Most of the institutions served primarily adults, usually comprising 60% to 80% of the total population. The two most common types of additional handicaps of the residents were mobility impairments and epilepsy.

The per capita expenditures of these institutions changed dramatically during the period under study. All institutions reported increases in per capita expenditures from 1972-75, with most reporting increases of 40% to 60% over this period. The total number of staff at the facilities also increased during this period, with increases of 6% to 14% reported by the institutions. The most common category of staff employed at the institutions was attendants.

3.3 State Context

All of the institutions felt that a policy existed at their facilities which set forth specific goals relating to the deinstitutionalization of mentally retarded residents. Seven of the ten institutions reported that this policy had developed through state legislation, regulations, or administrative guidelines; the remaining three felt that the institution had developed its own policy on this matter. Most of the institutions cited new state legislation in the areas of licensing, commitment, and guardianship and/or federal legislation such as the 1966 Community Mental Health and Mental Retardation Act, Title XIX of the Social Security Act, and the Developmental Disabilities Act as the major impetus in developing state or institutional policies for deinstitutionalization.

State "right to education" laws providing for the education of handicapped children existed in all of the institutions. These laws generally mandated public education for children of all handicaps at all levels of severity. The age range covered under the legislation varied from age 3, 4, 5, or 6 years through age 21 or 22. In most cases, institutions felt that the legislation had been only partially implemented at the time of the study interviews.

Five of the institutions reported that state "periodic review" legislation and/or policies existed which mandated that residents be reviewed on a regular basis by an interdisciplinary team to determine the appropriateness of continued institutionalization for each resident, and to document changes in each resident's condition. In the other five facilities, periodic review policy developed by the institutions themselves was reported. At all but one institution, a review of residents was mandated to take place at least once a year, with three facilities required to conduct these reviews every six months. One institution required reviews only every three years.

Eight of the ten institutions were located in states which were involved in class action or individual litigation concerned with mentally retarded individuals during the 1972-75 period. In five of these cases, the litigation was concerned directly with the institution studied; in the other

cases, the litigation concerned other institutions within the state. The most frequent types of cases cited concerned issues such as right to treatment, due process in commitment procedures, and protection against peonage in institutional jobs for residents. In most instances, these suits were in the process of being settled at the time of this study's interview.

3.4 Client Assessment Procedures

All of the institutions reported that psychological, vocational, medical, educational, and social assessments of residents were conducted. The frequency of these assessments varied from monthly (in most cases) to every two years or as needed. The assessments cited by institutions as being most frequently conducted were in the medical and educational areas.

Interdisciplinary staff teams, including physicians, nurses, social workers, psychologists, educators, and others, were involved in these client assessments, according to all of the institutions. In four of the institutions, families, guardians, or advocates of residents were generally invited to participate in these assessments. Less than half of the families invited ever participated, according to staff. In seven of the ten institutions, staff reported that residents often participated in these assessments, mostly by reviewing and discussing the assessment findings with staff. Other persons or agencies from outside the institution (e.g., rehabilitation agencies, consultants) were invited to participate in the assessments conducted at nine of the ten institutions.

3.5 Pre-Release Programs

At nine of the ten institutions, there were three to six pre-release programs designed to prepare residents for placement into community settings. (The remaining institution reported that it did not have specific pre-release programs for groups of residents; that instead, all programming was individualized.) Of the 38 pre-release programs across the institutions, 19 consisted of separate residential dormitories or wards designed to prepare clients for community living, 15 of which were vocational or pre-vocational programs (the majority being sheltered workshops on the grounds of the institution), and four of which were pre-release school programs located in communities near the institutions.

Major strengths of the pre-release programs most frequently cited by staff at the institutions were individualized programming for residents and the presence of positive, dedicated staff. The most commonly cited weaknesses of the pre-release programs as perceived by staff were lack of community resources and involvement, lack of skilled staff, lack of funds and other resources at the institutions.

3.6 Release Procedures

The release procedures which typically occur prior to a resident's release from an institution were quite similar across all of the institutions studied. Generally, interdisciplinary teams periodically review each resident's readiness for community placement. When a resident is considered ready for placement, the resident, parents, schools and/or community agencies are contacted for their input regarding available and appropriate placements. Once a placement is identified, the resident visits the setting on trial basis (ranging from one day to three weeks). If the trial visit(s) are successful, the resident is then released by the institution to that setting, usually on an "extended visit" or temporary basis as opposed to being formally discharged from the institution.

In most of the institutions, the large majority of residents were released primarily because of the institution's initiative (i.e., institutional staff felt that the resident was ready for release), as opposed to family initiative (i.e., the family requested that the resident be released). At all of the institutions, a resident released on an extended visit or temporary basis has the right to return voluntarily to the institution without regard to any waiting lists or waiting periods. This right is generally revoked once a resident is formally discharged. In half of the institutions, the superintendent or director did not have the legal power to return a released resident to the institution involuntarily. In the remaining five institutions, the superintendent could do so, but only through a court order and/or with court-committed cases.

According to staff at the institutions, the criteria most frequently used to determine whether a client is ready to be placed in the community are: functional level of the client; availability of residential placement

in the community; and, availability of day program alternatives in the community. There were striking similarities in the descriptions provided by staff at the ten institutions of the characteristics of clients considered easiest and most difficult to place in the community. Clients easiest to place were described in the following manner by staff at most of the institutions: good self-help, social, interpersonal, and communication skills; few or no medical problems; few or no behavioral problems; and normal appearance. Similarly, clients considered most difficult to place were most frequently described as: lacking self-help skills; having medical or ambulation problems or other handicapping conditions requiring a high degree of care; behavior/emotional problems; and abnormal appearance.

3.7 Follow-Up and Support Services

Follow-up contact, or efforts to keep track of where former residents are living, and how well they are doing in their placements, was considered the sole responsibility of the institution at three of the facilities. At four institutions, this responsibility was shared jointly by institutional and regional staff; in three cases, follow-up contact was not at all the responsibility of the institution, but rather was undertaken by the county or regional offices of mental retardation or welfare. Generally, institutions reported that released residents were followed up monthly. Sometimes, the frequency of follow-up was dependent upon the type of setting in which the resident lived--in two institutions, follow-up was much more frequent for residents in group homes than for those persons living with their natural families.

Similarly, with follow-up support services, the institution's responsibility for providing such services varied at the different facilities. In most cases, the institutions shared this responsibility with regional, county or community agencies; in most cases, institutions were responsible for providing support services only to clients released on an extended visit or temporary basis. The types of support services most frequently cited as being provided to released residents were social and medical services. Other supports included educational, vocational, recreational, and psychological services.

In most cases, support and/or training provided by the institution to families or caretakers of residents and/or employers/teachers of residents were limited or nonexistent. When such support was provided, it generally consisted of training in behavior modification techniques and individual counselling to families and caretakers, consultations and workshops for employers and teachers.

None of the institutions formally evaluated how well released clients were adjusting to life in the community, but most institutions informally assessed the adjustment of clients through discussions with staff, families, employers/teachers and through case reviews and reports. Most institutions felt that the majority of their released clients were adjusting extremely or very well. Similarly, it was felt that only a small percentage of clients were adjusting fairly or poorly (estimates of the percentage of clients in these categories ranged from 10% to 20%). The types of clients making an excellent adjustment to life in the community were most frequently described by staff at the various institutions as having: high functioning ability, lack of conflict in residence and day program, good motivation, good social and interpersonal behaviors, and general acceptance by the community. The following characteristics were most frequently used to describe those clients adjusting poorly to community life: behavior/emotional problems, medical problems, poor interpersonal/social relationships, and low motivation.

3.8 Profile of Released Clients and Re-Admitted Clients

This section presents some of the characteristics of the total released populations at the institutions (i.e., target clients plus non-target clients released during the 1972-75 period).* The percent of the total institutional population released into community and/or non-community settings varied greatly across the institutions, with ranges from 3% to 24% of the total institutional population. Most often, released clients were mildly or moderately retarded adults.

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* See Glossary for definitions of target and non-target clients.

The types of settings to which clients were released varied tremendously across the institutions. In general, more clients were released to natural homes and group homes than to foster homes, independent settings, or other institutional settings. However, the percentage of clients released to the different types of settings varied so much across institutions that no definite trends in placements can be identified.

The percent of target clients re-admitted to the institutions varied greatly, ranging from 1% to 50%. The majority of the re-admitted clients were adults who had remained in the community for six months or less. The settings from which these clients most frequently returned were natural families and group homes. The reasons most frequently cited by institutions for these re-admissions were: behavior problems or medical problems of the client; breakdown or closing of the client's "family" placement settting.

3.9 Overall Summary

Striking similarities across the ten institutions were revealed in the case study descriptions. Almost all of the institutions had experienced similar population trends, such as reductions in residential populations and increases in the proportions of severely and profoundly retarded residents. Deinstitutionalization policies, legislation, and litigation were present at all of the institutions. Client assessment procedures and release procedures were quite similar across the institutions. Although the number of pre-release programs varied at each institution, the types and ranges of programs did not differ in any substantial ways. Similarly, with follow-up services, the sources of follow-up varied somewhat, but the types of services and frequency of provision remained quite consistent. One of the most striking similarities revealed in the case study descriptions was the perceptions of staff regarding characteristics of residents easiest and most difficult to place in the community, and of residents making excellent and poor community adjustments. The descriptors used by staff to characterize these residents were consistent across almost all of the institutions.

The presence of these similarities, however, does not imply that there was no variation among the ten institutions. Although programmatically the institutions appeared quite similar, some demographic characteristics of the institutions did vary. For example, there was great variation across the ten sites in the percent of institutional residents released during the 1972-1974 period, the percent of residents released to the various types of community settings, and in the percent of clients re-admitted to the institutions.

4.0 SUMMARY OF VOLUME IV: DESCRIPTIVE DATA ON THE COMMUNITY EXPERIENCES OF MENTALLY RETARDED PERSONS

4.1 Purpose of the Report

All of the data collected from interviews with institutional staff, clients and their families, and from institutional records are described in this volume. The descriptions present a picture of the institutional and community experiences of 440 clients released from 10 institutions to community settings during 1972-74. It was decided to include these rather lengthy descriptions of the basic variables because of the inherent interest and potential usefulness they have for program planners and service providers. Since the more refined analysis provided in Volume V tends to lost the more qualitative sense of the data, the analysis offered in this volume provides an opportunity to describe the research findings in the most basic and least aggregated form.

4.2 Summary of Client Characteristics

The majority of clients in the study group were white adults, with an almost even distribution between males and females. Their average age at the time of the interview was about 27 years.

Slightly over 40% of the entire study group was mildly retarded -- more returnees* were moderately retarded than non-returnees, but fewer returnees were severely and profoundly retarded.

Returnees had slightly lower functioning as reported on Part I of the Adaptive Behavior Scale. On Part II of the ABS, however, returnees consistently scored higher, indicating more inappropriate social and personal behavior.

Most study group clients were of normal appearance, weight, cleanliness, etc. Over three-quarters of the group had no physical deformities. Approximately two-thirds of the clients had at least one additional disability other than retardation. For non-returnees, the most frequent additional disability was speech impairment; for returnees, psychological problems were the most frequent additional disability.

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*See Glossary for definitions.

4.3 Summary of Institutional Experiences

The institutionalization history of study group clients differed in many ways for non-returnees and returnees. Returnees were admitted to the participating institutions more times than were non-returnees, but had remained there for shorter periods (an average of 8 years for returnees, 11 years for non-returnees). The age at first admission to the institution also differed for the two groups--14 years for non-returnees, 17 years for returnees. Returnees were reported to have spent more time in other institutions than non-returnees. Thus, overall, returnees may have spent more time in institutions and may have moved more frequently from one institution to another.

One or more pre-release programs were participated in by approximately half of the study group clients. Residential pre-release programs and sheltered workshops were participated in most often, with competitive employment programs and school programs cited least often. One-fifth of the non-returnees, compared to only 10% of the returnees, were in a day activity located in the community prior to their release.

Most study group clients were reported to have basic grooming skills such as toileting, dressing, table manners, by the time they entered the community. Skill areas which residents were most often considered not ready to learn included using social and community agencies, vocational training, shopping skills, money management, using a telephone, and travel skills. Surprisingly, a much higher proportion of non-returnees' family respondents perceived areas in which skills should have been taught than the returnees' family respondents.

Study group clients participated in more individually-oriented spare time activities at the institutions than they did in group-oriented activities. Watching television or listening to the radio was, overall, the activity in which the largest number of people participated on at least a weekly basis.

About three-quarters of the study group clients had friends while they were living at the institution. Approximately two-thirds of the non-

returnees still visited or kept in touch with some of these institutional friends.

The types of information or records on the clients' institutional experiences and training most frequently provided by institutions to community residences were medical records. Less than half of both non-returnee and returnee respondents received information on the school programs, employment history, IQ or other test scores, institutional training, or financial situation of the study group members. Reports on the completeness and accuracy of the information provided varied according to the information type.

4.4 Summary of Community Characteristics

More non-returnee respondents than returnee respondents felt that various support services and training were available in their communities. Support services specifically for study group families were less available than services for the clients themselves, although some families reported the availability of consultation for handling specific problems and parent professional organizations.

In general, non-returnee respondents reported the client's day/work program and community agencies as the providers of the majority of services, whereas returnee respondents were more likely to cite the institution as the provider of services. Similarly, a much higher percent of returnee respondents cited the institution as a provider of training than did non-returnee respondents. Over three-quarters of the non-returnee respondents stated that they were satisfied with the support services available to the study group, while a little over half of the returnee respondents said they were satisfied.

Interviewers felt there was considerable community support for over three-quarters of the non-returnees, but for less than a quarter of the communities in which returnees were living prior to readmission. More non-returnee respondents than returnee respondents said that alternative residential settings (more supervised; less supervised) were available in their communities.

Non-returnee family respondents perceived the community as unfriendly to the client more often than they perceived the immediate neighborhood as unfriendly; returnee family respondents, however, had a higher percentage of responses indicating a friendly community and a lower percentage of responses indicating a friendly neighborhood.

4.5 Summary of Residential Experiences

Of the total study group (440 clients), 87% were currently living in community settings and 13% were interviewed after being readmitted to the institutions. The most common initial placement for all residents was a group home: over two-thirds of the non-returnees and half the returnees were initially placed in group homes. Almost one-third of returnees were initially placed in foster homes, compared to only 11% of non-returnees. More than a third of non-returnees and more than a quarter of returnees had lived in more than one residence since their release. Almost half of the non-returnees were living in group homes at the time of the interviews. Over 40% of returnees were living in foster homes prior to their readmission. The average length of time spent in these previous settings differed for non-returnees and returnees--7½ months for non-returnees and 4 months for returnees. Non-returnees had spent an average of 19½ months in their current settings, compared with only 11 months for returnees in the community setting prior to their readmission to the institution.

The overwhelming majority of non-returnees expressed satisfaction with their current residential setting. Only about half of the returnees indicated that they liked the residence in which they were living immediately preceding their return to the institution. More than one-third of the non-returnees, however, said they would prefer to live elsewhere, most frequently in their own home or apartment or with their natural family. About 40% of the returnees preferred to live elsewhere, most frequently indicating group homes or with their natural families. Virtually none of the non-returnees wanted to return to the institution, but over half of the returnees said they preferred the institution to the community.

4.6 Summary of Residential Characteristics

Group homes were the most common residential setting of non-returnees, whereas foster homes were the most common setting for returnees. The most common type of residence was a single-family dwelling located on a residential street. Group homes, semi-independent and independent settings tended to be closer to a shopping district and public transportation than were either natural/adoptive or foster homes. Most homes were rated in excellent condition and very clean. Independent living settings tended to get lower ratings on these dimensions than the other types of settings.

There was an average of 9 persons living in the homes, with higher averages in group homes than for other settings. Across all types of settings excluding natural/adoptive homes, the average length of time the home had been serving mentally retarded persons was three years. Very few homes had minimum or maximum stay rules. Group homes and semi-independent settings allowed greater percentages of non-returnees to engage in more activities than was found for natural/adoptive or foster homes--for example, in allowing clients to decide how to spend their own money, coming to and leaving their homes at will, drinking alcoholic beverages, and dating.

There were an average of three staff in group homes, and two in semi-independent settings; the majority of these staff served as house managers. Staff in group homes and semi-independent living settings had an average of 15 years of school, while natural/adoptive and foster home respondents were most commonly high school graduates.

The most frequently utilized support service by house managers and parents was consultation for handling specific problems. Community agencies were the major providers of support services, except for respite or relief from responsibilities (usually provided by the community residencies themselves). The service reportedly most needed but not received was support and/or training prior to the client's coming to the home. Natural/adoptive homes utilized fewer support services than any other type of setting, and more frequently said they needed but did not receive services.

4.7 Summary of Day Activity Experiences

About half the study group clients had a job placement, with three-quarters or more of them in sheltered workshop, rehabilitation centers, or job training centers. About 40% of the non-returnees and a quarter of the returnees were involved in a school placement, most frequently a class in a specialized school. About a quarter of all study group clients were involved in a day activity center or program. Less than 10% of the non-returnees had no day placement, while nearly a quarter of the returnees were not involved in a day placement immediately prior to their return to the institution. The reason most frequently cited by non-returnees and returnees without day placements was that there were not any appropriate programs available in their communities. While most clients were satisfied with their day placement, more study group clients in school or day activity centers were satisfied than were those in jobs. About half of the clients said there was something else they would prefer to do other than their current day placement. The most frequently preferred placement was competitive employment.

4.8 Summary of Services and Training

The four most frequently used types of services by study group clients were medical services, recreational services and social programs, dental services, and psychological services. Utilization of these services was higher for non-returnees than for returnees in all cases except psychological services, which were used more often by returnees than non-returnees. There were more returnees than non-returnees who did not receive services yet were perceived to need them.

The four most frequently used types of training by study group clients were in the areas of recreation, interpersonal relationships, behavior management, and meal preparation. Except in the area of behavior management, utilization of training was higher for non-returnees than for returnees, for those four types of training.

Residences and day/work programs were the major providers of training to study group clients. Community agencies and institutions were least frequently cited as providers of training.

More than half of all non-returnees and about three-quarters of returnees were followed up by staff from the institutions. Home visits were the most frequent method of follow-up, provided most often on a monthly basis.

The overwhelming majority (97%) of non-returnees and 66% of returnees were said to have a casemanager or someone responsible on an on-going basis for ensuring that the client received adequate services from appropriate sources. Houseparents were most frequently cited as the casemanagers of non-returnees, staff members from the institutions as those for returnees. More non-returnees than returnees had daily or weekly contact with their casemanagers.

More than three-quarters of all study group clients were said to have someone outside their home to turn to for support, guidance, or advice. Relatives and social workers were most frequently mentioned as the persons serving in this capacity.

4.9 Summary of Social and Civic Activities

Study group clients participated in more individually performed leisure time activities than group activities and did so at a higher frequency. The most common leisure time activities were watching TV or listening to radio, and going on errands. Activities that were least participated in were group activities including attending clubs, belonging to organizations and dating. Without exception, group activities were much more frequently participated in by non-returnees than by returnees.

Slightly more than half the study group clients were said to currently have good friends, most of whom were from the community (as opposed to the institution). More returnees than non-returnees were said to have no friends currently.

4.10 Summary of Problems and Overall Adjustment

In rating their overall adjustment, clients perceived themselves to be most competent in managing the relationships involved in community activities. Managing relationships with housestaff and siblings were regarded as most troublesome by clients. Families' perceptions of these relationships were quite similar to clients' own perceptions. The congruence of family and client perceptions was less likely in the case of returnees, who tended to rate their ability to manage relationships in various contexts higher than did the families.

Interviewers' ratings of clients on adjustment indicated many differences between the non-returnee and returnee groups, with the non-returnees always appearing more "adjusted"--more social relationships, less social isolation, higher ratings on happiness or satisfaction scales, more community support received.

Both non-returnees and returnees encountered problems living in the community, with the problems of returnees being of greater magnitude and occuring more frequently than the problems of non-returnees. Similarly, problems encountered by families of returnees in caring for the clients were larger and more frequent than those encountered by families of non-returnees.

Of the 58 returnees, the most frequently stated reason for return to the institution from the community was behavior problems. This response was also most frequently given by the clients themselves.

4.11 Overall Summary

This volume described the community experiences of study group clients. In general, these clients were faring well in the community. Of the total study group (440 clients), 87% were currently living in community settings at the time of the interviews; the remaining 13% had been readmitted to the institutions.

Most non-returnees were still living in their original placement setting at the time of the interview; the majority of them expressed satisfaction with their current residence in the community.

Most clients were involved in one or more day placements, such as jobs, schools, or day activity centers, and expressed satisfaction with their placements. In general, clients participated in a variety of leisure-time activities. Slightly more than half of the study group clients were currently said to have good friends, most of whom were from the community (as opposed to the institution).

Study group clients used a variety of services, and received training in many areas. Most clients were followed up by staff from the institutions, and were said to have a case manager or someone responsible on an on-going basis for ensuring adequate services for clients.

In rating their overall adjustment, clients perceived themselves to be most competent in managing their relationships involved in community activities. Managing relationships with house staff and siblings were regarded as most troublesome by clients. In general, families' perceptions of these relationships were quite similar to clients' own perceptions.

It is evident that the community experiences of non-returnees and returnees differed in each of the areas described in this volume. In general, non-returnees appear to have been more actively involved in their settings than returnees--e.g., in utilization of community support services and training, in participation in day placement activities, leisure-time activities, and friendships.

Moreover, non-returnees always appeared more "adjusted" than returnees on the interviewers' observation scales -- receiving higher ratings on the social relationships scale and satisfaction/happiness scale, and lower ratings on the social isolation scale. Similarly, the problems of returnees encountered while living in the community and the problems of their families in caring for them were of greater magnitude and frequency than those encountered by non-returnees and their families.

It is difficult, however, to interpret what these differences between non-returnees and returnees mean. Did the community experiences of non-returnees and returnees in fact differ, or were the returnees' perceptions of their previous experiences in the community biased? It is important to note that returnees were interviewed about their community experiences after they had already been reinstitutionalized. They may have tended to describe their community experiences negatively, since returning to the institution has traditionally implied failure. On the other hand, perhaps non-returnees tended to paint too "rosy" a picture of their experiences living in the community. Although interviewers reassured them that their responses would be held completely confidential, perhaps they were reluctant to give honest answers for fear that the information might be held against them.

Even assuming that the responses of both returnees and non-returnees were accurate, it is difficult to explain why these differences exist. Did these different experiences cause non-returnees to remain in the community and returnees to be reinstitutionalized? Or are these differences, instead, the effects of remaining in the community or returning to the institution? It was not the intent of this volume to explain or interpret the differences between returnees and non-returnees. This volume described these differences and raised some of the interpretive questions which should be addressed.

5.0 SUMMARY OF VOLUME V: AN ANALYSIS OF FACTORS ASSOCIATED WITH COMMUNITY ADJUSTMENT

5.1 Purpose of this Report

This volume presents the analysis of a final set of approximately 25 variables to determine which variables are associated with different aspects of "community adjustment." These final variables are divided into two main groups and a total of five groups altogether: predictor variables (individual characteristics, institutional experiences, institutional characteristics, community characteristics) and outcome variables.

5.2 Overview of Findings

The data reported in this volume point in a number of important directions for the future of deinstitutionalization efforts in this country. The key findings are summarized in this section. It is crucial to realize, however, that there are no clear determinants of "successful" adjustment, nor are there clear measures of "success." Rather, the processes being observed are extremely complex. This must be kept in mind in reviewing the specific findings summarized below.

1. The level of retardation of a mentally retarded person will have a direct impact on that person's "community adjustment."

Specifically, more retarded individuals will be less likely to return to the institution, to be perceived as having unmet needs than less retarded persons who will be more active and be living more independently in the community.

This finding strongly suggests that level of retardation per se should not be used as a determinant of whether or not a person can "make it" in the community. Indeed, persons of all levels of retardation can make it, and in some ways, perhaps because expectations are lower, more severely retarded persons might actually have less difficulty than less retarded persons.

2. The age of the mentally retarded person will have a direct impact on that person's adjustment to the community.

Specifically, the younger individuals will be less likely to return to the institution, and will be perceived as having fewer problems and unmet needs than adults who will be living more independently in the community than children.

This finding suggests that while people of all ages can and do "make it" in the community, that children are perceived as being somewhat easier to accomodate by the community than are adults.

(It should be noted that for our study group level of retardation and age were strongly related, with younger clients being more retarded. However, both age and level of retardation were found to have strong independent impacts on the various outcome measures used.)

3. The extent to which a mentally retarded person is involved in many activities in the institution prior to release has a direct impact on post-institutional adjustment.

Specifically, individuals who participated in more spare time and training activities were more likely to remain in the community to be more active upon release, to have fewer problems, and to have more independence in their living setting than study group members receiving less institutional preparation.

This finding is corroborated by the related finding that persons released from institutions which had more training available and which spent more money overall were less likely to return to the institution.

These findings strongly suggest that while individuals can and do "make it" without much prerelease preparation, that they are more likely to be successful than individuals without as much preparation.

4. The roles which institutions play in providing support to the community and to released clients has a strong impact on the adjustment which mentally retarded persons make in the community.

Specifically, mentally retarded persons released from institutions which prepare the community prior to a client's release do better, and persons released from institutions which provide a large proportion of services received in the community do less well. Mentally retarded persons released from institutions which provide support to the community prior to release of clients are more likely to remain in the community than are clients released from institutions providing less preparation. Conversely, mentally retarded people living in communities where a large proportion of services and training are provided by the institution are more likely to return to the institution, are living in less independent settings, and have more unmet needs.

These findings, combined with the previous findings, strongly suggest that the more the institution does prior to release the better off the client is, but conversely, the less the institution does after release the better the mentally retarded person does in the community.

5. The amount of support available in the community for mentally retarded people and their families directly affects other community adjustment.

Specifically, mentally retarded persons living in communities which have a wide range of services, training and residential options available do better than mentally retarded people living in less supported communities. The more support available in the community, the more likely is the mentally retarded person to remain in the community, to be more active, to have fewer problems, to have more independence, and to have fewer unmet needs.

This findings strongly suggest that if more community services are available, then mentally retarded persons will have better "adjustment" in the community.

6.0 POLICY RECOMMENDATIONS

This section will identify and summarize the major policy issues which emerge from the findings of this study. The policy issues will be organized into two major subsets, relating to: 1) the institution's role in the deinstitutionalization process, and 2) the community's role. These two subsets have been chosen because institutions and communities emerge in this study as the major facilitators of the community adjustment of deinstitutionalized mentally retarded persons.

Policy issues within these subsets will be identified, followed by supporting data and recommendations. The recommendations will focus on actions that may facilitate the community adjustment of mentally retarded persons. It is important to note that these recommendations will not pinpoint the locus of responsibility of these actions. We believe that these recommendations have implications for action at a variety of levels (e.g., federal, state and local) and for a variety of groups (e.g., particular agencies, organizations and programs). This project, however, did not study the specific mechanisms for implementing policies which exist at each of these levels and within each organization/agency.

It is our hope that the Bureau of Education for the Handicapped will explore the action implications of our recommendations at each level--there is a need to bolster the entire system which provides support to deinstitutionalized mentally retarded persons. The recommendations which follow have therefore been phrased broadly enough so that there are implications for persons and organizations at various levels of government, yet specifically enough so that they are substantive and directive.

6.1 Policies Relating to the Institution's Role in the Deinstitutionalization Process

- Policy Issue 1: Institutional Release Policies/Criteria--Placement of Severely and Profoundly Mentally Retarded Clients

The data both from our national mail survey of institutions serving mentally retarded clients and from our case studies of ten selected institutions indicate that a smaller proportion of severely and profoundly mentally

retarded clients have been deinstitutionalized than mildly or moderately retarded clients. Institutional staff interviewed attribute this trend to the pressures put on institutions to deinstitutionalize large numbers of clients and to their subsequent response of releasing their "cream of the crop" clients. But now that the "cream" has been skimmed, institutional staff feel that there remain in most institutions populations of clients more difficult to place, more severely and multiply handicapped, and those with behavior problems. The 1974 study by the National Association of Superintendents of Public Residential Facilities confirms these trends: the percentage of profoundly and severely retarded residents living in public institutions increased from 60% in 1974 to 71% in 1973 while the percentage of mildly and moderately retarded clients decreased from 35% to 26% during this 1964-1973 period.*

In our national survey of institutions serving mentally retarded clients, the largest group of released clients were mildly retarded (43%), and nearly a third were moderately retarded. Twenty percent were severely retarded, and the remaining 5% were profoundly retarded. Similarly, in our case studies of ten selected institutions, the majority of released clients were mildly or moderately retarded (mean of 62.5% across the institutions) whereas mildly and moderately retarded clients represented on the average only 24.9% of the total populations residing at these institutions during the 1972-75 period. The level of retardation of the 440 study group clients also showed a high proportion of mildly and moderately retarded clients--slightly over 40% of the entire study group was mildly retarded; and additional 30-40% of non-returnees and returnees were moderately retarded.

In our final study group were 106 severely and profoundly retarded clients. Information on their adjustment experiences may shed light on the future problems of placing more handicapped persons in the community. Our regression analysis indicated that people who were more retarded tended to have more problems in community living ($p < .001$), lived in more restrictive residential settings ($p < .001$), and had more unmet service needs ($p = .014$).

An analysis of variance yielded other significant differences with respect to the institutional and community experiences among clients of the

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* Current Trends and Status of Public Residential Services for the Mentally Retarded, 1974, National Association of Superintendents of Public Residential Facilities, p.6.

various levels of retardation. There was a definite trend (p = .102) indicating that severely and profoundly retarded individuals were actually less likely to return to the institution than more mildly retarded individuals. Also, the severely and profoundly retarded individuals were perceived as having less unmet needs than more mildly retarded clients (p = .001). One possible explanationpossible explanation for these rather surprising findings is the fact that society may have lower expectations for severely and profoundly retarded clients than are commonly held for higher functioning clients. That is, more severely retarded individuals are not returned to institutions as often and/or are not perceived as having unmet needs because traditionally they have not been perceived as having great potentials or needs. Perhaps it is easier for these clients to meet society's lower expectation than it is for more mildly retarded clients upon whom a higher set of expectations are often imposed.

Significant differences among all three levels of retardation were also found with respect to participation in spare-time activities and day programs prior to release and participation in spare-time activities once placed in the community. For each of these variables, profoundly and severely retarded clients had a lower frequency of participation than the mildly and moderately retarded individuals.

Our literature review indicated that, in the only study which has focused on the community adjustment of the "severely retarded" (I.Q. = 40-50) (Saenger, 1957), the experiences of the sample members (former pupils of special classes) were similar to the adjustment experiences of the severely and profoundly retarded clients in our study group--in terms of work experiences, social experiences, and interpersonal relationships. The data indicated that most clients had made good family adjustments, but continued to experience problems in finding and keeping jobs, participating in spare-time activities, and developing/maintaining friendships.

Recommendations

1) There is a need to explore why severely and profoundly retarded clients are not being placed in community settings. Specifically, institutional, community and individual factors inhibiting the community placement

of this population should be examined. Based on this information, strategies should be developed to help eliminate obstacles and to prepare institutions and community settings for the release and placement of these more difficult-to-place clients.

2) Special programs should be developed at the institutions to help prepare severely and profoundly mentally retarded clients for deinstitutionalization, and/or to prepare the community for their release. These programs should address the particular training and service needs of severely and profoundly retarded clients as indicated in this study--e.g., more training in management of behavior problems, in community living skills and use of leisure time activities.

3) Services and training addressing the particular unmet needs of severely and profoundly retarded clients as indicated in this study must be developed.

- Policy Issue 2: Institutional Preparation of Clients for Community Living.

Institutional preparation of clients for community living as measured by client participation in institutional day placements was strongly related to various aspects of community adjustment. For example, our analysis indicated that the more frequently clients participated in day placements when living at the institution, the less likely they were to experience problems when living at the institution, the less likely they were to experience problems in the community ($p = .046$), to live in a restrictive residential setting ($p = .078$), and to return to the institution ($p = .054$).

These findings regarding institutional training and community adjustment indicate a stronger relationship than has been demonstrated in other similar studies. Our literature review (Volume I) found that the experimental results regarding the influence of institutional work experience on later adjustment have been rather borderline in significance and/or in need of further investigation.

Three-quarters of the non-returnees and about two-thirds (69%) of the returnees were involved in a day activity in the institution prior to release. The most common placement was in a sheltered workshop at the institution or in the community (well over half of the non-returnees and over 40% of the returnees were in a sheltered workshop prior to release).

In our interviews with clients and their families about their institutional training experiences, most (about 90%) indicated that certain types of training (toileting, personal appearance, dressing, undressing, table manners) were either received at the institution or not needed because the client already had the skill. However, there were many types of training which family respondents felt were needed by clients to prepare them for community living, yet these were not provided by the institutions. The most frequently mentioned areas of unmet training need (cited by approximately 30% of the faimly respondents) were travel skills, using social and community agencies, dealing with emergencies, meal preparation, money management, using a telephone, and shopping skills. Of the skill areas mentioned when clients were asked what they would like to have learned, the most common areas cited were independence skills, domestic skills, and vocational skills.

It appears that clients and their families felt that institutions adequately prepared clients in the areas of very basic self-care skills. However, the scope and level of institutional training may have aimed too low, given the perceptions and expectations of clients and their families regarding training in the higher level skill areas described above.

Recommendations

1) More opportunities for clients to participate in institutional day placements and pre-release programs need to be provided prior to their placement into community settings. Our data indicated that large numbers of study group clients (more returnees than non-returnees) had not been involved in any day placements and prerelease programs prior to placement in the community.

2) Institutional training should address the types of skills identified in this study by clients and their families as important for community preparation and adjustment--namely vocational skills and skills in independnet community functioning such as using community and social agencies, dealing with emergencies, money management, using a telephone, meal preparation and shopping.

3) It is important that insitutions obtain more feedback from clients released into communities and from the settings in which they are placed

regarding the types of skills necessary for living successfully in the community. Pre-release and day placement programs would be most effective if they were designed to meet those specific training needs identified by communities and deinstitutionalized clients. At present, there is little, if any, sharing of this type of information between institutions and communities.

- Policy Issue 3: Institutional Services and Support.

The relationship of institutional services and support to the various community adjustment outcome variables is interesting. The higher the proportion of services available to clients living in the community through institutional providers (as opposed to community providers), the more likely are clients to live in more restrictive residential settings ($p < .001$), to return to the institution ($p < .001$), and the greater the unmet service needs of clients ($p < .001$).

Our data indicate that institutions are providing a large number of services to clients living in the community, particularly in the case of returnees prior to their readmission. In addition, institutional staff have served as casemanagers for clients in a large number of cases. It is difficult to determine why institutional services were found to be negatively associated with many of our community adjustment outcome measures. This is particularly puzzling given the strong positive relationship found between institutional support provided to families and employers of clients and community adjustment. For example, the more training provided by institutions to staff in community residences, the less likely are the clients they release to return to the institution ($p = .037$).

Recommendations

1) Given the many possible interpretations of these data regarding the relationship of institutional services to community adjustment, more research should be undertaken in this area. Specifically, the reasons why institutions maintained close ties with clients having difficulty adjusting need to be examined. Did institutional contact and support cause these clients to have difficulty adjusting or did these "difficult" clients necessitate the intervention of the institutions? Did institutions provide services

to clients because these supports were not available to clients through community agencies or were services available in the community but inadequate to meet clients' needs or unknown to clients? In short, the specific roles of the institution and community in serving deinstitutionalized clients and the relationships of these modes of support to community adjustment need to be examined further.

2) More training should be provided by institutions to families and employers of clients to prepare them for working/living with clients in the community given the strong positive relationship found between these variables and various measures of community adjustment. This training should include consultation of specific problems/needs of clients, service resources available and behavior management issues.

3) Institutions should strive to have community agencies provide services directly to deinstitutionalized clients since community provision of services was found to be positively correlated with community adjustment and institutional provision of services negatively associated with many of our community adjustment outcome measures. This is <u>not</u> to say that institutions should <u>cease</u> providing services to deinstitutionalized clients -- it appears that institutional services are necessary as stop-gap measures until all deinstitutionalized clients are adequately served by community providers. Our data do <u>not</u> demonstrate that services provided by institutions to clients living in communities are more detrimental than no services at all. It does appear, however, that community provision of services to clients is more likely to facilitate their community adjustment than institutional provisions.

- Policy Issue 4: The Institution's Continuing Responsibility for Deinstitutionalized Clients

In our interviews with institutional staff about their deinstitutionalization procedures, it became evident that support systems for deinstitutionalized clients were viewed by most institutions as the responsibility of the communities, not the institutions. Staff indicated that there is a great ambiguity regarding the legal responsibilities of institutions and community agencies toward clients place in community settings. In most cases, there were no clear-cut guidelines regarding which agency or

agencies maintained primary responsibility for ensuring adequate services for released clients. Many clients and their families may therefore fall into the "cracks" of these agencies' mandates. Generally, a variety of agencies, both institution and community based, were involved, but primary responsibility for service delivery was often difficult to identify.

Furthermore, there is a lack of sharing of information about clients between institutions and community agencies, which was evident both from our interviews with institutional staff and interviews with deinstitutionalized clients and their families. Institutions, in many cases, felt that sharing certain types of information about clients with "outside" community agencies violated the confidentiality and right to privacy of clients. Community agencies, on the other hand, frequently felt that institutions were denying them information about clients essential to adequate delivery of services.

Recommendations

1) The roles of institutions and community agencies in ensuring adequate service for released clients should be further investigated so that specific guidelines regarding the relative responsibilities of those two agents can be specified. Our data suggest that ultimately community agencies should assume primary responsibility for ensuring adequate service delivery (see discussion of Policy Issue 3), but until that time when community agencies do, in fact, assume this role, the responsibilities of both the institutions and communities should be spelled out through policies and legislative action at all levels of government. This will prevent clients from falling into the "cracks" and not being served by any providers.

2) Mechanisms should be developed between institutions and community agencies for the sharing of information about clients placed in community settings and their needs, in order to facilitate adequate delivery of services to these clients.

6.2 Policies Relating to the Community's role in the Deinstitutionalization Process

- **Policy Issue 5: Availability of Support Services and Training Opportunities in the Community**

The availability of services and training in the communities was one of the strongest predictors of community adjustment revealed in our study. It was found that people living in communities which have fewer services and training provided or available were more likely to have problems in community living ($p = .084$), to live in restrictive residential settings ($p < .001$), and to be readmitted to the institutions ($p = .088$); and were less likely to be actively involved in day placements ($p < .001$) and spare-time activities in the community ($p < .001$).

It is interesting to note that non-returnees tended to receive their services and training more often from community agencies or from their community residential settings, whereas returnees were more likely to use institutions for services and training while living in the community. In the stepwise regression analysis, the availability of support services in the community was found to be a strong ($p = .088$) predictor of the outcome variable, remaining in the community. The relationship between the availability of community services and training and community adjustment needs to be explored further. One hypothesis which needs to be explored is whether the availability of these supports in the community enable the non-returnees to function in the community and the lack of these supports in the community cause the maladjustment problems of the returnees. More information must be gathered on the <u>actual</u> availability of community supports (as opposed to clients', families' and institutions' <u>perceptions</u> of availability) before questions such as the one above can be addressed

Recommendations

1) As discussed above, more research should be undertaken on the availability of community services and training for deinstitutionalized clients. For example, studies of the current service and training capabilities of community agencies should be conducted, addressing the capacities of communities (including social service agencies, schools, hospitals, etc.) to meet the diverse needs of the deinstitutionalized clients and the necessary steps needed in order to increase their capacities to serve this population.

- Policy Issue 6: Types of Services and Training Provided in the Community

There were various types of services provided to study group clients by various provider sources. Non-returnees received these services most often from community agencies, while returnees were more likely to use institutions for services while living in the community. For example, for at least a third of returnee users, institutions provided medical, dental, social/psychological, camp, and housing assistance services; whereas there were no services that institutions provided which were utilized by as many as a third of the non-returnees.

A higher degree of unmet service need was found in the case of returnees than non-returnees. The types of services most frequently cited as being needed by clients but not received were speech therapy, occupational therapy, and camp for 16% or less of the non-returnees; and social and recreational services, medical services, and psychological counseling for 20-25% of the returnees.

Regarding availability of training opportunities, it became evident that the need and desire for training does not cease once a client is placed in a community setting. Clients were receiving training in a variety of skill areas while living in the community, most frequently in recreation (80% of non-returnees, 60% of returnees), interpersonal relationships (77% of the non-returnees, 69% of returnees), behavior management (70% of non-returnees, 74% of returnees), and meal preparation (73% of non-returnees, 55% of returnees).

The types of training most frequently cited by respondents as being needed but not received (for 10% or less of non-returnees, 15-25% of returnees) were generally in higher level skill areas such as language, reading and writing, money management, dealing with emergencies, vocational skills, and using public agencies.

When clients were interviewed about the types of skills they wished to learn in the community, they mentioned training in areas similar to those described above -- most frequently reading and writing and money management skills. These data indicate that clients aspire to higher level training than is currently provided to them.

Recommendations

1) More services and training opportunities should be made available in the community to deinstitutionalized clients, particularly in those areas of unmet need identified by clients and their families.

2) Training opportunities in higher level skill areas should be provided, given the stated aspirations of clients and the families' perceptions of client need. These skill areas include reading and writing, money management, dealing with emergencies, using public agencies, and vocational skills.

- Policy Issue 7: Availability of Residential Settings in the Community

In our national survey of institutions serving mentally retarded clients, the most common type of community placement to which clients were released was natural/adoptive homes (40% of clients). Over a quarter (29%) of the released clients were placed in group homes. The survey also indicated that the types of community placements utilized by institutions varied considerably in the different regions of the country. These variations may indicate the range of available community residences, as well as reflect the types of target clients released. For example, it is interesting that Southern institutions in our study released nearly two-thirds of all target clients to natural/adoptive homes, while North Central institutions placed nearly half of all released clients in group homes. The North Central

and Southern institutions were much less likely to place target clients in foster homes than were institutions in other regions. In the Northeast and Western areas, overall releases were fairly evenly distributed among natural/adoptive, foster and group homes.

What are the implications of these varying residential placement patterns? The availability of different residential placement settings was found to be an important variable in our analysis of factors associated with community adjustment. For example, clients living in communities where a variety of residential options (more supervised and/or less supervised residences) were available were more likely to be involved in day placements ($p < .001$) and were less likely to have problems in adjusting to community living ($p = .002$). Another interesting finding was that returnees were initially placed in foster homes more often than were non-returnees (32% of the returnees, 11% of the non-returnees), and that the residential setting of returnees immediately prior to their readmission was most often foster homes (as opposed to foster homes serving as the current residential setting for only 14% of the non-returnees). It is difficult to hypothesize why foster home placements were so much more frequent in the case of returnees as opposed to non-returnees. But this trend should certainly be explored in more detail in the future -- for example, are the training experiences of foster home parents more limited than those offered to caretakers in other settings? Are the services and training opportunities available to clients in foster homes more limited than in other settings? Or are persons perceived as "higher risk" placed into foster home settings more often than in other settings?

Recommendations

1) A variety of residential options (both more supervised and less supervised) should be made available to clients in their communities, given the strong positive relationship found between this variable and some of our measures of community adjustment.

2) There is a need to investigate the various types of residential settings available in terms of their capacities to meet the diverse needs of deinstitutionalized clients. One of the major research questions to address

is: are certain types of settings more appropriate to clients with particular sets of needs? Related to this question, the high proportion of returnees in foster home placements should be investigated further. Specifically, the reasons why returnees are more likely to be placed in foster homes need to be examined -- e.g., is the higher proportion of returnees in foster home placements due to the fact that foster homes are generally inadequate to meet the needs of deinstitutionalized clients, or rather that foster homes are more willing than other settings to accept these more-difficult-to-place clients in the first place?

3) More training and support should be offered to families/staff in residential settings in order to help them assist deinstitutionalized mentally retarded clients adjust to the community. This seems particularly crucial in the case of foster home parents who served a higher proportion of clients who eventually became returnees.

- Policy Issue 8: Availability of Day Activities in the Community

Involvement in day activities -- work, school, day activity centers -- was used in this study as a measure of community adjustment. About half of both non-returnees and returnees had a job, either in a competitive situation or a sheltered workshop. About 40% of the non-returnees and only 24% of the returnees were in day or night school; while only 9% of the non-returnees had no day placement, nearly a quarter of the returnees were not involved in a day placement immediately prior to their return to the institution.

The lack of involvement in day activities is a serious problem, apparently of greater magnitude for returnees than non-returnees. The reason most frequently cited by study group clients for not being involved in day placements was that there were not any appropriate programs available in their communities (33% of non-returnees' reasons, 55% of returnees' reasons). Only in 19% of the non-returnee cases and 9% of the returnee cases was the lack of involvement due to the client's lack of interest/willingness to participate.

Recommendations

1) More day placement activities appropriate to the needs of deinstitutionalized mentally retarded clients should be made available in communities.

2) Competitive employment opportunities for clients need to be explored/developed. Clients expressed preference, most frequently, for regular competitive jobs. (Of those clients who had jobs, less than one-fourth were in competitive employment placements.) Perhaps, the training for and placement of more clients in competitive employment situations would help to alleviate another problem frequently expressed by clients and their families: the lack of pay or low pay received by clients in their work situations. (For those clients who were paid at their work placement, non-returnees averaged about $20 per week compared to an average of $10 per week for returnees.)

- Policy Issue 9: Problems in Community Living

The most serious problems in adjusting to the community identified by both families and clients were in the areas of behavior management and interpersonal relationships -- particularly behavior problems, loneliness, problems with family relationships, and social relationships. These problems were cited more often in the case of returnees than non-returnees.

Families of non-returnees rated job problems (26% of non-returnee cases) and family relationships (15% of non-returnee cases) as the most serious problems which they encountered in caring for clients. Families of returnees felt that the clients' behavior/discipline problems were the most serious (58% of returnees), followed by meeting residents' psychological needs (29%), and stress on family relationships (26%). Moreover, the reason most frequently given by returnees (43%) for returning to the institution from the community was behavior problems. In addition, analysis of factors associated with community adjustment indicated that a higher score on the Adaptive Behavior Scale's negative behavior items was significantly related to overall problems in community living.

Behavior problems were also identified by institutional staff as major obstacles to community adjustment. When institutional staff were asked to describe the clients whom they felt were easiest to place and most likely to adjust in the community, lack of behavior problems and good interpersonal relationships were the characteristics most frequently identified.

Recommendations

More services, training and support in the areas of behavior management and interpersonal relationships should be provided, given the large number of problems in these areas by clients, families and institutional staff. These supports should be provided directly to clients as well as indirectly to the families caring for them.

6.3 Conclusion

This study has investigated the roles of various actors in the deinstitutionalization process, including deinstitutionalized clients, their families/caretakers, community agencies, and the institutions. What is evident from the policy issues identified in this section is the need to integrate the responsibilities and functions of these various groups in preparing, placing and assisting clients living in community settings.

The actions necessary to facilitate deinstitutionalization and community adjustment are clear and have been delineated in this section. What is more difficult to establish, however, is the roles of these various actors in the process. For example, our data stress the importance of institutions in preparing clients for placement and developing/supporting community alternatives. Our data also point, however, to an extremely active role for community agencies and residential settings in this process. What is crucial now is the development of clearcut policies and legislative actions which clarify the responsibilities of these various actors in the deinstitutionalization process -- both at the institution and in the community, and at the local, state, and national levels. Defining the roles and responsibilities of these various actors, determining their current capacities to serve this population, and developing legislative and financial

policies to support them in their actions, remain the next critical steps toward facilitating the community adjustment of deinstitutionalized mentally retarded persons.

It is difficult to summarize the major findings of this study because the outcome measures and predictors of adjustment were multiple and their relationships complex. There are, however, some major thrusts of the data which emerge throughout our findings and relate to the roles of institutions and communities in the deinstitutionalization process.

Regarding the role of institutions, our data point to the fact that the more the institution does prior to release in terms of the intensity of programming provided to the mentally retarded person, the more the institution does to prepare the community for the resident; but the less the institution does once the client is in the community (in terms of the proportion of services provided) the more likely it is that the mentally retarded person will remain in the community after release. Regarding the community, our data show that the greater the types of support available and provided to mentally retarded persons living in the community, the better is their "adjustment" -- i.e., they remain in the community, are more active, have fewer problems, live more independently and have fewer unmet needs.

Although the actual direction of these institutional/community relationships cannot be clearly established, our data strongly suggest that institutions should concentrate their efforts on preparing clients and communities for release and that communities should assume the responsibility for providing supports to clients once they are released into community settings. We have found that the adjustment of clients tends to be problematic in those cases where institutions have provided supports to clients living in the community. One possible explanation for this fact is that institutions often serve as a fall-back for mentally retarded persons who live in communities which do not have adequate support services; this fall-back role is insufficient to retain the individuals in the community satisfactorily. The policies outlined in this section point to efforts which will: 1) enable institutions to cease serving as the fall-back provider and instead concentrate their efforts on intensive pre-release preparation,

and 2) enable communities to develop and provide adequate support services for mentally retarded clients living in community settings.

Our data have shown that a large group of mentally retarded persons is adjusting to community living according to a variety of criteria. The positive implications of these findings must be stressed. That is, in spite of inadequate institutional and community supports cited frequently by respondents, clients are generally adjusting well. It remains to be seen how much better they might fare if they were provided the supports which have been identified in this report as essential to successful community adjustment. If clients have been able to adjust as well as they have without adequate supports, their potential for higher levels of adjustment and growth in the future remains unlimited. It is hoped that implementation of the policy actions outlined in this report might help to realize some of this unmet potential.

6.4 Additional Recommendations for Future Research

There are various approaches to assessing the community adjustment of mentally retarded persons, which should be explored in future studies. This section summarizes this project and the literature review of previous research in this field. Some of the future directions which should be explored include:

- Multi-dimensional Approaches to Assessing Community Adjustment

Our data and the findings of other studies indicate that there are various components or dimensions of community adjustment. Unidimensional approaches which use a single homogeneous criterion (such as recidivism) to measure community adjustment are inadequate because they fail to capture the complexity of the adjustment process. People function in a variety of environments which place multiple demands upon them. There is a need to explore different success criteria for different persons in different settings.

Future longitudinal studies should ideally gather information about clients before their release into community settings as well as several points in time after community placement. This type of approach would allow measurements of change in clients' adjustment over time. It is difficult to

determine how long the time-frame in these assessments should be. The few longitudinal studies which have been conducted vary in the time span from 12 to 30 years. It may not be necessary to conduct longitudinal studies of such duration, but certainly measurements should be conducted at several points over a three-to-five year span upon release.

- Studies Measuring Community Adjustment Relative to Various Environments

What constitutes adjustment for a person in one environment might not be considered successful in a different environment. Adjustment is relative to the individual person and the specific demands and expectations of his/her environment(s). Most of the studies to date have suffered from an almost exclusive emphasis on variables associated with the individual, rather than with the nature of the environment and its demands. Our study, in limited ways, attempted to include measures relating to community characteristics and demands. However, these types of variables have rarely been used in previous research, are often extremely difficult and costly to conceptualize, measure and collect.

Given that community adjustment represents an interactive process which is relative to environment, follow-up studies measuring community adjustment must focus not only on how the individual adapts to the demands of his/her community, but how the community adapts to the demands and needs of the individual. Measuring a community's adaptation to the demands and needs of an individual is extremely difficult. Little has been done in this area, and what little has been done has often been vague and ineffective. Community variables such as indices of community support services, community's toleration of deviance, socio-economic characteristics of the community, etc., and the relationships of these variables to the community adjustment of mentally retarded persons ought to be explored.

- Comparative Studies of Community Adjustment

Comparative studies offer a unique perspective on community adjustment because the experiences of mentally retarded persons are examined in relation to the other persons living in the community, usually groups of non-retarded persons. This type of study is difficult to undertake because

of the problems in selecting an appropriate "control" group and because the study procedures are more costly and time consuming due to the enlarged study sample. However, comparative studies are extremely valuable because only in these studies can we determine how the adjustment experiences of mentally retarded persons compare to the so-called "normal" population's experience. This becomes particularly important, given one of the problems identified in this study's literature review: many of the criteria used in measuring community adjustment may impose higher standards for mentally retarded persons than would be expected of the so-called normal population. Comparative studies would prevent researchers from imposing different standards for mentally retarded and non-retarded persons. In addition to using non-retarded persons as control group members, it would also be interesting to explore other comparison groups such as mentally retarded persons still living in institutions, or mentally retarded persons in the community who have never been institutionalized. Differences among these various groups would enhance our knowledge of the community adjustment process.

- Studies Incorporating Clients' Perceptions of Their Community Experiences and Adjustment

Few studies have attempted to interview clients directly for their opinions on their community experiences and adjustment. We feel that our efforts in this area proved extremely useful -- we were able to obtain the client's perspective on many issues related to community adjustment. However, more research should be done in this area -- particularly on the effective structuring of questions and of the interview process so as to enable clients to respond most directly and honestly. Also, the most effective means for analyzing and reporting client data needs to be examined; because clients had difficulty in responding appropriately to closed-ended questions, the resulting data were not very useful for analytical purposes. However, client data were used most effectively in straightforward descriptive reporting; their insights and feelings about their institutional and community experiences provided a unique perspective on the process of community adjustment.

- Studies Examining Factors Affecting Release of Mentally Retarded Persons from Institutions

The findings of our study and of previous studies indicate that certain types of clients are released from institutions more frequently than other types of clients. For example, in both our study of 440 deinstitutionalized clients released from the ten selected institutions and in our national survey of 154 institutions serving mentally retarded persons, a higher proportion of mildly and moderately retarded clients of "normal" appearance and without additional handicaps, were placed in community settings than severely and profoundly retarded clients of "abnormal" appearance and with additional handicaps. A further and more detailed examination of the factors and criteria used by institutions and communities to determine which clients get released would prove extremely useful.

- Studies Focusing on the Community Adjustment of Severely and Profoundly Retarded Clients

In our interviews with institutional staff, they indicated that institutions have already released their "cream of the crop" clients -- e.g., mildly and moderately retarded clients without major problems. Currently and in the future, institutions and communities will be faced with placing more severely retarded clients in the community, who often bring with them additional physical, medical and other problems. A study focusing exclusively on the placement problems and adjustment experiences of severely and profoundly retarded clients would provide information to program planners on the needs of this new group of community residents.

It is important to build on the studies which have been done in the past and to move in new research directions. Our review of the literature in Volume I indicated that a large group of descriptive follow-up studies has already been conducted. The recommendations outlined in this section point to the need for more analytic, systematic, and comprehensive data gathering in the future.

APPENDIX

GLOSSARY

Additional Handicapping Conditions: These refer to handicaps other than mental retardation, including visual or auditory impairments, mobility limitations, psychiatric problems, or epilepsy.

Age Group: Target clients were grouped into two age categories: ages 18 and under were considered children and youth, while adults were those clients between the ages of 19 and 40 years.

Casemanager: This term refers to anyone in the community who is responsible on an on-going basis for ensuring that a person receives appropriate services and support.

Client Assessment Procedures: Steps used by the institution to assess or review the needs and progress of residents while living in the institution. Includes both the formal psychological and educational testing and informal judgments by staff.

Community: This refers to the setting in which the individual is placed when released from the institution. "Community" must be viewed broadly and includes the following contexts: individual's place of residence, place of work, and places of social activity. This includes, as well, the immediate neighborhood and the larger surrounding community.

Community Adjustment: This study assumes that community adjustment is a two-way process: 1) the process of the individual adapting to the demands and requirements of daily living in a community as opposed to an institutional setting; and, 2) the process of the community adapting to the demands and needs of the individual. The adaptive behaviors necessary for community living which this study examines include measures of personal, vocational, social and civic adjustment. This study also assumes that there are no rigid criteria for defining "successful" or "unsuccessful" community adjustment. Rather, the concept of adjustment is relative to the context of the community setting in which the individual is living (including the individual's residential, work and social settings). Ideally, in order to get a total picture of the community adjustment process, the adaptive behaviors of the individual to these contexts must be studied as well as these settings' adaptation to and acceptance of the individual.

Community Placement: May include natural homes, foster homes, cooperative apartments, group homes, as well as independent living units. However, in this study, community placements do not include residential settings which are as restrictive or as sheltered as the institutions from which clients were released (e.g., nursing homes, state schools, and state hospitals) nor are any residential settings serving over 100 persons considered a community placement.

Deinstitutionalization: In its most limited and narrow sense, deinstitutionalization refers to a planned reduction in the number of persons residing in institutions for the mentally retarded. However, for the purposes of this study, a broader definition has been utilized.

Deinstitutionalization in this study, refers to the process of placing mentally retarded persons from institutions into community based settings (see definition of community placement). This process includes the following interrelated activities: 1) the on-going assessment of clients in institutions to determine their readiness and appropriateness for community placement; 2) the preparation and training of clients at the institution in skills necessary for eventual community placement; 3) the procedures undertaken by the institution to secure and/or develop community placements for residents; 4) the follow-up efforts on the part of the institution to monitor the progress of residents in their community placements and to provide any assistance to facilitate the community adjustment of former residents. This study focuses on deinstitutionalized clients between the ages of 6 and 40 who have been placed in community-based residences following their enrollment in residential institutions (facilities serving over 100 handicapped clients) for two years or more.

Discharged: A mentally retarded person is considered to have been discharged if s/he is no longer officially on the rolls of the institution. Some institutions automatically discharge residents when they are placed in the community; others place residents in the community on a trial basis before formally discharging them (see "Extended Visit").

Extended Visit: A mentally retarded person is considered to be on extended visit status if s/he is living outside the institution but is still officially counted on the rolls and is considered to be part of the institution's clientele. Other terms used by institutions to indicate an extended visit status include "temporary discharge" or "trial leave." The exact minimum and maximum lengths of extended visits involved are likely to vary from institution to institution. This status is often the first one used when a person is initially placed in the community on a trial basis from the institution until reasonable assurance of successful community adjustment has been obtained.

Follow-Up: Any effort made on the part of the institution to keep track of where former residents are living, and how well they are doing in their new placements, including direct contact with the released resident or contact made with responsible social workers, employers, or residential staff of the released resident is considered to be follow-up.

Follow-Up Support: Any assistance which an individual mentally retarded person receives which facilitates his/her adjustment to community placement. Follow-up support services are typically received through a resident's social worker or through institutional services available for released clients.

Institution: Any environment which provides a "total care" system for handicapped clients within its physical boundaries. Most, and in many cases, all human services including shelter, food, medical care, recreation, habilitative and/or educational services, etc., are provided for clients on the institution's grounds. For the purposes of this study, a facility had to serve over 100 residents in order to be considered an institution.

Institutional Control: This term refers to whether the institution is privately owned and controlled, or whether it is a publicly operated facility.

Institutional Staff: Information was collected on the number of staff employed at the institutions for the following positions: administrators, medical doctors, psychiatrist, psychologist, social workers, therapists, rehabilitation/vocational counselor, nurse, attendant, teacher, support staff, other staff.

Levels of Retardation: The levels of retardation used in this study are mildly retarded (IQ 68-72), moderately retarded (IQ 51-36), severely retarded (IQ 35-20), and profoundly retarded (IQ 19 and below). These are the levels and definitions used by the American Association on Mental Deficiency (AAMD). Mild retardation is roughly equivalent to the educational term "educable;" moderate retardation includes those individuals who are likely to fall into the educational category of "trainable;" the severe group includes individuals sometimes known as "dependent retarded;" individuals in the profound retardation level are among those sometimes called "life support" level.

Non-Returnees: Members of the study group interviewed while they were living in the community. They were the people who had remained in the community since their release from the institution, or who, if they had returned to the institution, had been released again.

Non-Target Clients: Non-target clients are all clients released from an institution between 1972-1974 who do not meet the criteria specified for inclusion in this study (i.e., they can be less than 6 years or more than 40 years old, have been in the institution for less than 2 years prior to release, and/or have been placed in non-"community" settings such as nursing homes, state hospitals, etc.). (See below.)

Overall Releases: This refers to the total number of clients released from the responding institutions between January 1, 1972 and December 31, 1974 who were between the ages of 6 and 40 years at the time of their release and who had resided at the facility for at least two years prior to their release. The type of placement to which the client was released was not specified for this count and thus, the overall release number includes both target and non-target clients.

Periodic Review: This is a procedure, often mandated by state legislation, through which residents in institutions (or other state programs) are evaluated on a regular basis. The objective of this review is usually to determine the appropriateness of the current programming for a client and to provide the basis for revised programming if appropriate. Thus, periodic review is often performed by an interdisciplinary team which examines a broad range of capabilities and achievements in an individual client. The state legislation usually prescribes the frequency of the periodic review (e.g., at least once a year) as well as the nature of the review (e.g., it must include a psychological review, an intelligence test, etc.) and even the participants in the review (the professionals to be involved and the role of parents). New York, Pennsylvania, and Massachusetts are some of the states which have passed such laws.

Post-Release Services: Many institutions provide continuing support for released residents. These support services may include medical and dental care, social services and counseling, and/or respite care.

Pre-Release Program: Many institutions have developed special programs which are specifically designed to prepare clients for placement into community settings. These programs provide training in various skills considered necessary for living in the community. The programs include separate residential facilities on the institution's grounds which are developed to prepare residents for the demands of community living, sheltered workshops, competitive work placement, and schools either within the institution or the community. Typically, different programs exist for children and for adults. A few institutions consider all their efforts to constitute "pre-release" programming.

Region: Institutions responding to the Institutional Mail Questionnaire were grouped into four geographic regions as follows:

Northeast: Connecticut, Delaware, Maine, Massachusetts, New Hampshire, New Jersey, New York, Rhode Island, Pennsylvania, Vermont.

North Central: Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, Wisconsin.

South: Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, West Virginia.

West: Arizona, California, Colorado, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, Wyoming.

The institutions in the states of Alaska and Hawaii were not included in the Institutional Mail Questionnaire.

Released: A person is considered released from the institution when s/he has been placed in the community either on a formal discharge or extended visit status (see definitions of these terms in the Glossary). A person is not considered released when the placement is only for a short period of time (e.g., a week's leave) and when return to the institution is expected or required.

Release Procedure: This refers to either the formal or informal process established within an institution for the selection of and eventual release of an institutional resident.

Returnees: Those members of the target group of released clients who had returned to the institution. The term is used in this project to refer to those individuals who were back at the institution when the interviews were conducted.

Right to Education Law: This refers to state legislation which provides for the education and training of handicapped children within the public school system. Generally, right to education laws mandate that all children (regardless of level of retardation or level of handicap) have the right to a public education--either in a special education class or in a regular classroom program. In some states, the law applies to children from 0-21 years. In other states, the age range may be more limited.

Study Group: This refers to those target clients who were contacted with the assistance of the institutions for Abt Associates and subsequently agreed to participate in the study. Study group members, therefore, are a self-selected sample of the released target group.

Study Group Respondents: The term "respondent" refers to the study group's contact person interviewed in the community about the study group member's experiences since release. Respondents were, in general, a natural/adoptive parent, a foster parent, a group home manager, or a social worker. The respondents gave information on the institutional follow-up provided, on the existence of a casemanager, on the study group member's residential and day activities history, on the types of services and training received since release, and on the types of problems encountered by the study group.

Support Services for Clients: Interviewed study group respondents were asked about twelve types of support services which may have been available in the community. These support services on which information was collected were: medical services, dental services, social/psychological counseling, job counseling and/or evaluation, camp, recreational/social programs, occupational therapy, speech therapy, physical therapy, legal assistance, housing assistance, and other support service.

Support Services for Families: Study group respondents were asked about six types of support services which may have been available to them in the community. These services on which information was collected were: support and/or training prior to client's coming to the residence, on-going counseling for the family, consultation for handling specific problems, respite or relief from responsibilities, parent or professional associations, and other services used or needed.

Target Clients: Target clients refer to those mentally retarded persons between the ages of 6 to 40 years who were released between 1972 and 1974 into a community setting other than a nursing home or residential facility serving 100 or more persons after having resided at an institution for at least 2 years prior to their release. Released clients who meet this definition constitute the primary group of deinstitutionalized clients selected for study in this project. The distinction made between target and non-target clients is solely a function of this study and does not indicate a distinction made by institutions or institutional personnel.

Training: Interviewed study group respondents were asked about 24 skill areas in which the released group may have received training since their release. These training areas were: eating (self-feeding and table manners), toilet use, cleanliness (washing, personal hygiene), dressing and undressing, personal appearance (posture, neatness of dress), motor skills, sensory (hearing and vision), language (speech, comprehension), pre-academic skills (shapes, colors, sizes), numbers and telling time, reading and writing, pre-vocational skills, vocational training, housekeeping, meal preparation, traveling skills, using a telephone, money management, shopping skills, dealing with emergencies, using social and community agencies, interpersonal relationships, behavior management, and recreation skills.